

**DISABILITY THROUGH A GLOBAL LENS:
UNDERSTANDING DISABILITY IN CULTURAL CONTEXTS**

Undergraduate Honors Research Thesis, Disability Studies

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INTRODUCTION: GLOBAL SHIFT FROM MEDICAL TO SOCIAL MODELS

I. Background and Literature

Multiculturalism is rapidly emerging as a force in our healthcare, educational and political fields. In order to adequately understand, devote resources to, and help cope with disorder and disability in our increasingly diverse world, cultural competence has become a pillar of care and treatment. To ensure the highest quality of understanding and allow professionals to be most effective in their fields, we must comprehend and engender respect for different cultures. One area in which this is particularly important is in developmental and physical disability. Over one billion people, or around fifteen percent of the world's population, currently live with some form of a disability (World Health Organization). Universally, many people and children with disabilities face barriers. As a result of the broad nature of disability, which encompasses a vast range of disorders, syndromes and delays, it is especially critical for us to learn about how this is defined, understood, and managed by different peoples and societies. Understanding differences in perceptions and viewpoints of different countries, cultures, governments, medical systems and individuals is necessary in order to create societies in which individuals treat people with disabilities with respect and dignity.

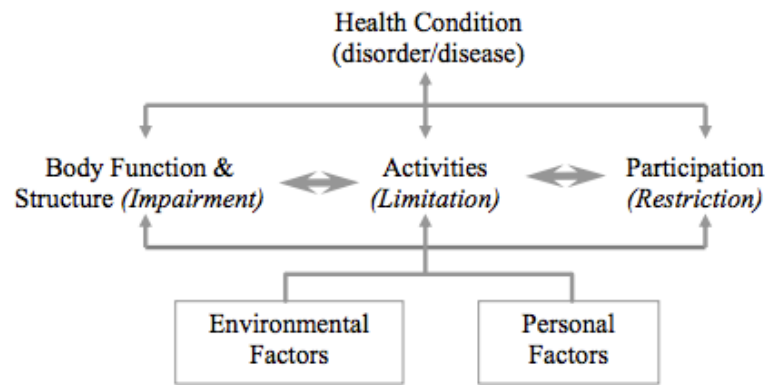
The literature presents disability as a global issue, sharing a sense of fundamental commonality but also varying in essential ways. Nora Groce, disability researcher and medical anthropologist, claims that "in all societies, individuals with disability are not only recognized as distinct from the general population, but value and meaning are also attached to their condition" (Groce 6). Although there are underlying similarities in perceptions of disability, the differences across cultures are vast. Gartner and Lipsky state that, "responses to disability are not 'natural' rather they are invented, different at one time or another, from one culture to another, from the

perspective of one discipline or another” (Gartner & Lipsky 112). Disability can be interpreted in a multitude of ways and each culture and group generates its own social construction of it. These definitions shape how disability is treated and how individuals with disabilities function as community members in contrastive cultures.

One major issue in the literature about disability is how to measure it on a global scale. Because there is no completely valid and reliable basic system that we use to measure disability across cultures, this poses challenges in the ways disability can be compared across settings. In a paper on measuring disability and health, Daniel Mont states “disability and health are difficult concepts to define and measure. In fact, the appropriate definition of disability depends on the reason behind its measurement” (Mont 1658). The measurement of disability is also dependent upon the view of disability an individual holds. Most prominent in disability studies today is the social model. This approach holds that “disability arises from the interaction of an individual’s functional status with the physical, cultural and policy environments” (Mont 1659). Studies have attempted to generate international prevalence rates, however these tend to produce variable results dependent upon differences in how disability is defined, distinctions in methods and processes and the quality of the study design.

The International Classification of Functioning (ICF) attempts to measure functionality and disability through incorporating a social model approach. This diagram uses multiple interactions to explain that people are classified based upon a variety of social domains rather than solely their health. In contrast to this, a medical model diagram focuses solely on the individual problem and the health condition and disorder/disease (Mont 2).

Figure 1: The ICF Model



While this model integrates the many aspects related to having and living with a disability, it is extremely difficult to quantify all of these variables and score them on one instrument. Daniel Mont outlines several categories important to discovering the general disability prevalence including: difficulty in core activity (seeing, hearing, walking), a measure of mental functioning (including a focus on memory/concentration), the absence of assistive devices, and a measure that provides information about severity. Additionally, using the word ‘disability’ in measures may bias participants due to the negative stigma associated with the term. Another significant challenge is that people with cognitive and developmental disabilities, including many children, may not have the intellectual ability or capacity to answer these questionnaires, making it even more difficult to quantify these types of disabilities (Mont 20). The universal definition of disability recognizes its wide span, but describes it as a combination of factors including health conditions blended with environmental elements (World Health Organization). Today, policy makers are progressively adopting a social model orientation in thinking about and advocating for the disabled population. The literature also emphasizes provision of culturally competent services and the idea that disability experiences in different cultures cannot be homogenized. While it is important to try to understand disability on a global

scale, much of the research emphasizes the importance of understanding in smaller domains and at community levels.

A 2013 United Nations Children's Fund report discusses the global state of children with disabilities. It estimates that on average, ninety-three million children, which is about one out of twenty (ages fourteen and younger) have a moderate or severe disability of some form. However, it warns that this statistic may not be fully accurate because "definitions of disability differ by place and time" (UNICEF 3). This describes the importance of understanding that location and development influence our changing views of disability. The report focuses on the changing of attitudes and perceptions of children with disabilities, claiming that only with these attitude changes will children with disabilities be included, accepted and treated with respect. The recommendations include creating inclusion across all domains of life. In addition, this report links the poor quality and lack of appropriate data on child disability with the following facts: (1) that we have a limited understanding of disability in many cultures, and (2) stigmas and/or invisibility of children with disabilities. Because it is difficult to conduct quantitative research on global disability, this leads to inaccuracies in definitions and ultimately mistreatment, discrimination and challenges for children and adults with disabilities throughout their lives. This may be especially true in resource poor areas in which education and access to resources is limited.

II. A Case Study Approach: Otavalo, Ecuador and Jerusalem, Israel

This honors thesis research examines disability as a construct through multiple angles, using a variety of viewpoints to create an image of how children with disabilities are perceived in two distinct cultural settings. The proposed research project asks the following questions: How is disability defined in this culture? How are children with disabilities treated in society? What

factors play a role in influencing definitions and interpretations of disability? What are similarities and differences across and within sites? Through adopting an ethnographic fieldwork approach including participant observation and informal interviews, supplemented by intensive literature review, this thesis draws upon and emphasizes important factors in how disability is viewed, defined and treated in two distinct cultures in Otavalo, Ecuador and Jerusalem, Israel. The participants in this research study include: therapists, teachers, social workers, psychologists and other staff members employed at centers for children with disabilities at each site. Through discussions and observations with these subjects at each site, the research extracts three major clusters of factors that subjects noted as playing a role in how society and individuals view disability. These three sets of factors are: (1) access to resources, (2) legal and educational structures, (3) ethnicity and religion. In addition, the literature on global disability emphasizes these components of how culture influences treatment of disability.

III. Overview of Case Study Sites

The findings of this fieldwork research represent an analysis of each community, and serve as case studies that depict how disability is interpreted and treated in different settings. The case studies specifically address perceptions of disabilities within the context of children, because the fieldwork data collection took place at centers for children with disabilities. While participants in these case studies work directly with children, many of their insights address disability in a broader context and the research also draws upon literature that addresses disability across ages, gender and social categories. The process of choosing research sites involved taking into account potential challenges in addition to areas of curiosity. For example, when conducting independent, international research, it is important to communicate with participants in their own language. Therefore, I knew I would need both Spanish and Hebrew

language skills to conduct the study, two languages in which I have a background of knowledge. I also knew that there were several factors I was interested in comparing and understanding across the two sites, for example, differences between a modern versus less developed nation, and how income and socioeconomic status influenced differences. For this reason, I focused my search on research sites in Central and South America in Spanish speaking countries where I knew I could both conduct research successfully using the language and engage in research in a less modern country. Another factor I wanted to investigate was religion. In Israel, a country with no separation of church and state, religious views play a prominent role in shaping laws, societal values, norms and perceptions. After a thorough process of discussions with professors across departments at Ohio State, consulting with the Office of International Affairs on campus and connecting with partners overseas, two centers for children with disabilities were selected and participants at each site agreed to be a part the study.

A. La Joya: Otavalo, Ecuador

In Ecuador, the volunteer site was in Otavalo, a town in the northern Imbabura province of Ecuador with a population of about 90,000. The population of Otavalo consists predominantly of indigenous Andean groups and mestizas, or people of European descent. The volunteer site, *La Joya: Centro De Desarrollo Para Niños con Discapacidades* (The Jewel: Center of Development for Children with Disabilities), serves as a school and therapy center for fifty four children from ages zero through twelve with a wide range of physical, developmental and intellectual disabilities. Most of the children at the center are of indigenous descent and come from villages surrounding the town of Otavalo, in the area known as “la sierra” (the highlands). The children receive specialized education curriculum along with therapy services at the center

including speech, physical and psychological therapy and also including family sessions with a social worker.

B. Shalva: Jerusalem, Israel

In Israel, the site of research is *Shalva: The Association for Mentally & Physically Challenged Children in Israel*, located in Har Nof, an Orthodox Jewish neighborhood with a population of 20,000 on the western border of Jerusalem. Shalva provides a wide variety of services to children with a range of disabilities at many different ages. At the research site, I spent most of my time in the rehabilitative day care program, working with toddlers with Down syndrome and collecting data from their teachers, aides and therapists. However, I also learned about and observed the after school activity center program, for older children ages six through twenty-one and the overnight and weekend programs in which children and young adults enjoy a night per week or month out of their house, participating in activities and therapy services at the center with friends and staff members.

IV. Methodologies and Limitations

This thesis uses a combination of methodologies to answer research questions of perceptions of disability at each case study site. Before conducting international fieldwork, the literature on cross-cultural disability was reviewed in order to learn about what work in this area of study already exists, and what researchers have found thus far. In order to conduct research on individualized definitions, perceptions and treatment of disability, it is critical to understand the present challenges that researchers have regarding these areas. The existing work suggests that disability is prevalent across different fields and can be written about and researched in many ways. There is no one standardized measurement of disability, and estimates on global rates, prevalence and existence of disability are speculative.

Primarily, this fieldwork experience relied on my immersion into each setting as a volunteer, spending extensive days participating in a wide range of activities at the two centers for children with disabilities. One benefit of being in this role was that it allowed for naturalistic observations. As a volunteer who spent extensive hours each day at the center, I was able to observe routines and patterns, note conversations and interactions and ask questions in a naturalistic setting. Rather than setting up a study in a clinical laboratory or in a location unfamiliar to the participants I was able to conduct my research at their places of work, to which they were accustomed and felt comfortable. This is important because the staff, including teachers, therapists and aides served as subjects and primary sources of data. Their insights provided rich qualitative information about how children with disabilities are treated both at the centers for the children and in context of the greater community. These individuals were selected to be participants because they have an understanding of how children with disabilities are treated and perceived in the context of special environments created for them (at La Joya and Shalva) and through their daily life experiences in their communities as well.

The use of informal interviews and conversations also allowed me to engage with these individuals directly and in ways comfortable for them. Participants were able to direct conversations and because the basis of the interviews was discussion, developing these bonds with participants allowed them to feel comfortable sharing what wished and steering conversations. This is beneficial because it allowed participants to be more honest and open. When asking questions, I framed them openly and they differed based upon the context. For example, at the center in Ecuador, several of the staff members were also parents to children with disabilities who received services and were in classrooms at La Joya. Within this context, it was important to be frame questions differently to those who were parents, taking into account

sensitivities that come with having a child who has a disability and how these experiences may differ from those who do not have children with disabilities.

There are many situations in which research questions and methodologies may place individuals in situations that are not comfortable for them, such as asking culturally insensitive questions, or talking to participants in front of parents or families, or in languages they do not understand. Because parents were often present throughout each day at both sites in therapy sessions with children, observing classrooms, or picking or dropping their children off, this is one factor that I remained sensitive to throughout my research. I made sure to keep conversations that might involve sensitive issues in private settings, rather than in the classroom or therapy session.

Although there are many benefits to using these approaches, there are also several limitations. Through asking open-ended questions and allowing individuals the flexibility to share whatever information they wanted, it was sometimes difficult to obtain exact answers to research questions. Along with this, without always asking specific interview questions, it was sometimes challenging to get information about the same topic at each of the settings, making it more difficult to draw upon distinctive similarities and differences. This relates to the limited generalization of this research study. Although it constructs an understanding of views of disability at a community level, there are few generalizations that can be made to broader settings. For example, the Orthodox Jewish community in which I conducted research in Israel placed a heavy emphasis on religion as a factor in defining disability. While this is clearly evident in this community, it cannot be generalized to the entire country or even the city of Jerusalem. After speaking with social workers and occupational therapists in secular communities, I learned that religion played much less of a role in perceptions and treatment in

non-Orthodox communities even within the same city. This example represents a major obstacle to the generalizability of this research, and it is to be viewed as a case study work that provides vivid examples rather than a study representing overarching definitions of disability in two large cultures or countries. Although the research cannot be generalized to a wide extent, there are some areas in which data recorded throughout each case study may be representative of the entire culture. For example, laws about education and employment are in many cases national, and thus definitions of disability can be influenced at broader levels by such laws that contribute to societal norms and values.

Along with this, barriers effecting the limitations of the research also included language and cultural barriers. While I took measures to integrate myself into each culture ranging from staying in homes of families native to the communities, to taking lessons to improve upon my foreign language skills, to utilizing public transportation, it is impossible to remove research bias and occupy the role of someone native to the community. In addition, it would be impossible to fully integrate myself into these communities because my cultural, ethnic and religious background is different. With this comes the understanding that participants at each site did not view me as a member of their community, rather as an outsider, and this also may play a role in impacting their actions and our discussions. It is possible that participants gave answers that they thought I might be looking for, or changed their actions to conform to the stereotypes they might hold of Americans. The methodology used required me to take into account my own lens and become aware of my expectations and assumptions.

With Spanish being a language of proficiency, and not a native tongue, I often found myself asking people to repeat themselves, or asking them to clarify what they said. In these situations, a translator dictionary was particularly helpful, and provided for enhanced

comprehension. However, without being a fluent speaker it is impossible to understand everything that is said and occurs both in regard to language and cultural norms. There was a noticeable difference in this personal experience across the two research sites; with fluency in Hebrew, and having traveled to Israel many times, it was much easier for me feel comfortable in the international setting and have a more comprehensive understanding of the language and cultural values. I utilized a field note taking method to record all of my observations, conversations and interviews with great detail. This daily writing and synthesis of field notes allowed me to also track my research and progress throughout the experience. Upon the completion of the fieldwork, the field notes allowed me to extract major themes and patterns relevant to the research questions.

V. Ethics and Informed Consent

At each research site, informed consent paperwork was used to explain the process of the study to allow participants to fully understand the nature and purpose of the research. The paperwork also included discussion of benefits and risks of the research. In this case, there were no potential risks, and also no immediate benefits to the individuals participating. The benefit of the participants' contributions was focused on helping to compile data about perceptions of disability in unique cultural settings that would contribute to the thesis work and the ultimate goal of informing others about important differences and similarities about the treatment and views disability across cultures. I worked with native language speakers to translate these forms into both Hebrew and Spanish in order to allow the reader to fully comprehend the purpose of the research and determine in which way they chose to participate and be identified in the work. According to the National Institutes of Health Clinical Center Department of Bioethics, there are four key elements of informed consent, the first being competency of the subjects. Each of the

subjects was mentally capable and able to comprehend the consent form and process, as it was translated into their native language and I was able to field and answer questions in each language. The second element is full disclosure to participants about the study. This was successfully achieved through the listing of goals, benefits and risks of the study within the form, and through allowing and encouraging any questions and open communication about the study. This ensures the third element, understanding, is achieved, through also posing questions to ensure the participants comprehend the purpose of the work, and answering any questions they have. For example, one participant asked if their name would be used in the work; I directed them to the portion of the form that allowed them to select whether they wanted their contributions to be anonymous, or named. The last element is that the participation of the subjects must be voluntary. The consent forms stated the following, in order to make subjects were made aware of their voluntary participation: “You can refuse to take part in the study, and may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your participation in the study is voluntary.” Thus, the informed consent process used at each site in this research meets the guidelines proposed by the National Institutes of Health (Emanuel, Abdoler & Stunkel). The Office of Responsible Research Practices Ohio State University Institutional Review Board approved the human subjects study (Protocol Number: 2013B0153). After completing the paperwork, the participants remained informed throughout the fieldwork by being provided giving the opportunity to read any field notes and repeatedly discussing the purpose of the project.

VI. Importance and Applicability

At each site, I spent one month working with children with disabilities and their social workers, psychologists, physical and speech therapists and other supports and caretakers. I observed their daily routines and patterns, taking extensive field notes and discussing research questions with staff members. Within each context I uncovered many similarities and differences both within the community and in comparison to each other through observational fieldwork and conversations with informed research subjects. This thesis utilizes qualitative data acquired through ethnographic fieldwork along with relevant literature to assess similarities, differences and discuss the importance of understanding cultural values and perceptions. The project applies to many different professions, and serves as an example of the importance of understanding how culture can influence views and treatment of disability. In order to help professionals care for and support people with disabilities across a multitude of backgrounds, it is crucial to build these frameworks through understanding both unique circumstances and factors that play a role globally. Throughout the work, the research discusses perceptions and treatment in critical areas including access to resources, educational and legal systems, religion and ethnicity. Each chapter synthesizes fieldwork and literature to build descriptive case studies of the sites across these areas. In addition, although this research is focused on studying disability, the framework of the project serves as a lens to examine cross-cultural perceptions. Within the fields of social and behavioral science, it is necessary to understand that differences exist based on a variety of factors. Particularly in helping professions, it is important to understand how and why these viewpoints differ. This research study, in addition to investigating perceptions and definitions of disability also addresses broader-spanning topics such as: why it is meaningful to understand different cultural perceptions, what factors influence these perceptions, and how this translates from the world of research to the lives of individuals, communities and society.

CHAPTER 1: ACCESS TO RESOURCES

I. Introduction

Access to resources is a critical determinant of societal functioning, impacting values, norms and views. Unequal access to resources, or a lack of resources altogether contributes to perceptions of disability in communities around the world. When discussing cross-cultural disability, it is impossible to ignore access to resources as an influential factor in both treatment of people with mental and physical impairments and societal views of disability. Disabled populations globally often fall below the poverty line. This may be due to a variety of factors ranging from educational obstacles and challenges, to fewer opportunities to earn substantial income, to incurring high medical expenses. Along with this, the level of access to economic, medical, educational and therapeutic resources often are barriers to individuals with disabilities. Access to these critical resources varies across countries, communities and individuals. Being able to access and utilize resources is important in not only contributing to the lives of people and children with disabilities, but also to how communities perceive them. For example, in communities where the overall population has a lower education level, there may be fewer individuals who have had opportunities to learn about disability in a formal setting and instead depend on informal knowledge passed down by societies and families. These understandings of disability can be both positive and negative, but often rely on storytelling and belief systems rather than scientific knowledge.

It is important to consider that there are individual differences in how access to resources impact the lives of people with disabilities and how community members conceptualize disability based upon their differential levels of access. In the case studies in Ecuador and Israel, access to resources was a topic constantly brought up by participants at both research sites.

However, even within each community, there were drastic individual differences observed and discussed. For example, one participant at La Joya described a scenario in which two families with children with autism resided in similar rural communities an hour commute from the city of Otavalo, worked in agriculture making an income below poverty level, and had similar access to medical care, but viewed their child's disability through drastically different lenses. In one family, the father refused to accept his child's diagnosis, and believed that he should not attend a special school or receive any therapy services. He claimed that being surrounded by children with disabilities was bad for his son, and wanted to remove him from the center and send him to a typical school in the city. In the other family, the parents were not only accepting of their child's disability, but maintained a positive outlook, and attended therapy sessions and meetings with the center's social worker in order to learn more and support their child. In this particular case, two families from similar backgrounds with comparable access to resources have very different definitions and treatments of autism. This example serves to represent the existence of individual differences even when resource access and lifestyles are similar.

At both case study sites, access to economic, medical, educational and community resources consistently came up in discussions with professionals serving the children with disabilities. Within each of these domains, subjects believed that limitations of resources contributed to the societal views and treatment of the children at each center. Along with this, therapists and teachers also noted when resources were existing and easily accessible in the community, and how this also played a role in defining disability as a construct. This chapter will explore how having different levels of access to resources within the domains of economics, medicine, education and therapy influences how children with disabilities are viewed and treated.

Although access to resources is applicable beyond each of these categories, these were the areas of discussion most frequently mentioned by research subjects at La Joya and Shalva.

II. Economic Resources

Economic resources relevant to the conceptualization of disability in each case range from funding support of each center to family income level and socioeconomic status. La Joya receives funding from both public and private sources. The main source of financial support is from a philanthropic foundation *Fundacion Sepla Ayuda*, based in Spain. Along with this, La Joya also receives donations from the city council of Otavalo, however this support is minimal and covers only the children's meals at the center each day: a simple breakfast of bread and hot cereal and lunch including small portions of meat, rice and a side vegetable. Additionally, other organizations including small nonprofits and individual donors help to support the center.

Fundacion Sepla Ayuda currently faces an economic crisis situation related to the global state of the economy, particularly in Spain. Due to these financial challenges, the foundation will no longer be able to contribute funds to the center this upcoming year and La Joya is in the process of seeking and requesting funding from other sources. This portrays the link between the international economy and supporting children with disabilities. Many centers around the world depend upon private sources of funding to provide education and therapy services to children, so when economic difficulties pose challenges for such groups, centers and organizations that advocate and provide services to children with disabilities and their families also suffer. The annual operating expense for La Joya is \$300,000 USD – and each year, *Fundacion Sepla Ayuda* provides 80% of the funding, or \$240,000 USD. If the center is no longer able to keep its doors open due to a lack of funding, the community will lose its only inclusive center for children with disabilities, and many children will no longer receive education and therapy services. According

center did not exist (Caicedo, Interview). Because many of their families live in low income homes in distant communities, opportunities for children with disabilities are rare and those who are physically capable often work in the fields with their siblings and parents to help families make an income. Those who have physical impairments are often confined to their homes. Many do not have wheelchairs in their homes, and it is only during their time each day at the center in which they have wheelchairs they can use. In addition, for those who live in mountainous regions without concrete roads and sidewalks, the use of wheelchairs would not even be an option, and in these cases children learn to adapt and utilize resources available to move around. These barriers in access to full economic resources that centers for children with disabilities face demonstrate how such resources at a structural level can greatly impact daily lives for children with disabilities in this community.

At Shalva, the economic support for the center is similar to La Joya in that 75% of the funding is received from philanthropic donors. The Israeli government provides the remaining 25%. Shalva differs from La Joya in that it incorporates a wider variety of programs to a larger span of ages. It also is housed in much larger physical space than La Joya, therefore allowing them more opportunities to include larger numbers of children and families and space to run their programs. Along with this, Shalva is not currently facing the same challenges in funding that are occurring at La Joya. Donor support for Shalva remains high and the organization's leadership is not currently in an emergency economic state as at the Ecuadorian site. Shalva is focusing on their new building of a larger and more inclusive facility in a different location in order to continue to expand and grow, while La Joya is focusing on simply attempting to retain the space and resources they currently have. In this case, donations and funding have increased yearly, thus the center developed economic resources allowing it to grow and develop, and in turn continue to

reach out to people with disabilities in Jerusalem to provide a larger population support and care. This exemplifies ways in which having access to money at an institutional level can benefit both individual lives and overall societal perceptions. At the new campus of Shalva, currently in the process of its construction, there will be an outdoor playground accessible to all children, not just those with special needs. This proves that with continuing donor support, these organizations have access to financial resources that allow them to implement initiatives promoting inclusion and integration. This example that portrays how economic resources at an organizational level can create changes through cultivating new projects, making a difference in the lives of individuals with disabilities and the ways in which communities perceive them.

Participants at each center also strongly emphasized how economic resources impacted the lives of children with disabilities on an individual level, in their homes, and how these levels affect the ways children are treated and defined in the context of family life. At both research sites, the demography of the child populations included very large families, both Orthodox Jews and indigenous Andean groups. At La Joya, the social worker discussed a student's living situation, explaining that because of a lack of money her family of seven is forced to live, sleep and eat in two rooms. According to the participant, this contributed to immense stress in the family, and caused many negative perceptions of the child with autism. The child's siblings viewed her as a stressor in their lives and were constantly concerned with whose turn it was to look after her, care for her and ensure she was safe (Bolaños, Interview). This depicts how having a low level of access to financial resources can be an impactful stressor in the lives of families and children with special needs. When meeting with the center's speech therapist and the child's sibling, she repeatedly described her sister as very difficult and emphasized how life with her was challenging. When asked what her sister liked to do and was good at, she was only

able to name three activities and things, however when asked what was most challenging about her, she was able to list several challenges, including bathing, ensuring she didn't run into the street, sleeping at night, and feeding her meals. Because this family struggled to make a reasonable income, with a mother and grandmother supporting the household after the death of the father, daily life was consistently more difficult in comparison to families with higher income levels. This combined with the stress of caretaking were related in many circumstances to individuals having negative perceptions of children with disabilities and defining them as challenges and difficulties rather than unique individuals with varying sets of skills and interests. This finding is very logical; it is inevitable that lower income leads to increased levels of stress and thus it is rational for caretaking and views of children with disabilities to be negatively skewed in difficult life circumstances. While many families experience this life stress in relation to economic resources, it does not foster negative interpretations of disability in every case. In indigenous communities, which are collectivist in their culture rather than individualist, it is also common for families to hold inclusive views of disability. While economic challenges faced by these individuals have the capacity to negatively influence views, this culture of interdependence may also ensure that children and adults with disabilities in the community are not left behind and instead take on responsibilities and roles. Economic resource access is important, however it is intertwined with other factors that play a larger or smaller role based on the specific circumstances.

At the site in Israel, there were also several examples participants used to describe how having different levels of family income influences views and treatment. A teacher at Shalva described to me a child with Down syndrome living with eight siblings and young parents, which is typical of the Orthodox Jewish tradition. This family lives in a small apartment in the Har Nof

neighborhood of Jerusalem. In their home, all eight children sleep in the living room space attached to the kitchen. Similarly to the example noted above at La Joya, this family makes a minimal income that in turn must support a large number of children. Having a child with Down syndrome contributes additional finances to the family's life, including medical costs, therapy services and other supports. Along with this, having a child with a developmental delay increases stress levels, particularly in low-income homes. However, the research participant described this family as "hopeful" and said that they viewed their child with Down syndrome as a blessing from God, and a "light in their lives" (Anonymous Participant 1, Interview). Although the caretaking of a child with a disability may be burdensome, this family perceived their child as bringing joy and fulfillment despite the difficulties. These two examples depict how even in similar circumstances, the ways in which individuals view children with disabilities can differ considerably. These two descriptions do not encompass the views and experiences of all families at the site in Ecuador or every individual at the site in Israel. Along with this, these descriptions were provided through the medium of the research participants commenting on their experiences with families and children; therefore there is inevitable bias in their views. It is crucial to understand that these examples portray the notion that even in stressful situations of low-income families lacking financial resources, views and perceptions can differ. While most participants described situations in which limited monetary resources contributed to negative perceptions of disability, there were some exceptions, as described above, in which even in difficult economic circumstances, it is possible to cultivate positive conceptualizations. Although living in poverty or struggling to support a family clearly impacts stress levels, in these special cases in which families are able to develop positive frameworks of disability, there are often other factors that are deemed more important and are more salient in those peoples' lives. This allows for

minimizing of negative understandings and the maximizing of positive views. For example, for individuals rooted in collectivist cultures, it may be extremely important for everyone to be included in helping in the community work; for people who have deep religious beliefs and values, this may play a larger role in defining disability than economic context. Ultimately, differential levels of income and severity of economic challenges contribute to constructs of disability, and the strength of this role is mediated by other factors including religious values and cultural norms.

III. Medical Resources

Access to economic resources is inextricably linked to ability to reach a variety of other supports that play a role in the lives of families of children with disabilities. According to the 2013 UNICEF report on children with disabilities, families that are living in poverty often also experience a lack of access to hospitals, medicine and medical care (UNICEF 1). The influence that access to medicine has on shaping perceptions of disability differs based upon healthcare legislation and medical systems in place. In both case studies, the research participants discussed how access to medical care, doctors and hospitals influenced not only the children at each center, but also the level of knowledge and awareness that members in the community have regarding disability. Although neither center provided medical services, they both offered forms of therapy including animal therapy, music therapy, psychological care and treatment for both children and families, speech therapy, occupational and physical therapy. Therefore, many of the children at each center had access to therapy and met with therapists ranging from daily to weekly. At La Joya, physical, speech and stimulation therapy were offered. According to the physical therapist at La Joya, these children were extremely fortunate to be able to receive this support at the center. She explained that many of the parents and families did not have therapy services before

enrolling their children at La Joya, and that private therapy services are expensive and out of the realistic spending range for many families (Esparza, Interview). This challenge is one that many families face in regards to access to medical care globally. Distance, education and income all contribute to a family's ability to seek and attain medical care for their children. One research participant at La Joya explained that receiving medical attention is very difficult not only because a lack of money, but also because of a lack of doctors in general. There is only one pediatric neurologist in the region, and a consultation with this doctor costs approximately forty dollars. The subject explained that most families at the center made an income of at most, two hundred dollars each month (Esparza, Interview). Thus, a consultation appointment with a neurologist costs about 20% of the family's monthly income. For many families, this is not a priority. In addition, a lack of access to transportation makes it increasingly difficult for families to take their children to see doctors.

The social worker at La Joya described inadequate access to medical care through discussing the specific example at the center. Three children with whom she works have a genetic disorder called *mucopolysaccharidosis*. This disability causes a variety of physical effects, and also slows neurological growth and development. This family lives in a rural community, with limited access to technology. The parents of the children were unaware that their children's disorder was genetic, and until their oldest daughter was six and their youngest son was two, they did not have a diagnosis for their children. Although they were aware that their children clearly had special needs, they did not have access to medical care to attain necessary treatment. Previous doctor visits did not answer questions and local doctors were unable, or unwilling to deliver diagnoses. One day, the mother of the children was at a store in Otavalo and saw an infomercial on the television, flashing photographs of children who had very

similar appearances to her own. She continued to watch the screen and learned that it was playing an advertisement for a center in Quito that treated children with a particular disorder, mucopolysaccharidosis. Because she was sure that these children closely resembled her own and identified an opportunity to possibly receive support and medical care for her children, she traveled to the capital city to take her children to the center where they were immediately diagnosed with the disorder and given medication and advice. With these medications and the support of doctors, the family has been able to work to fulfill their children's needs and send them to La Joya so they can continue to receive therapy and an education closer to home. In addition, receiving medical diagnoses informed the parents of the genetic nature of the disorder, which could have implications for their possible future plans of having more children. This situation illustrates the difficulties that families of children with disabilities face in supporting their children due to a lack of knowledge about and access to medicine and healthcare. The social worker speculated that if the parents were aware that the diagnosis was genetically based when their first child was born, they might have made different choices about having children (Bolaños, Interview). At Shalva, one subject described a scenario in which the parents of a child with a cognitive impairment had developmental disabilities themselves. This family also struggled due to having limited knowledge about and access to doctors and treatment. During the case study, this child took a fall at home, and ended up with a large bruise and scrape on her face. When she came into the center following this incident, her eye was swollen, black and blue. After speaking with the child's classroom aide, I learned that her parents were not aware that a minor injury could become an infection. They also didn't know where or how to take their child to go see a doctor and receive any prescriptions to prevent infection, or advice on keeping their daughter well. This represents a challenge faced by families in which parents also have

disabilities, and their capacity to reach out and receive necessary health services may be impaired.

IV. Levels of and Opportunities for Education

Access to medical care and resources clearly impacts the lives of individuals with disabilities and influences the way others define it. One therapist at La Joya explained that because children, siblings and parents have minimal access doctors, medications and therapy, they are less educated about the disability and thus less equipped to explain, define and help the community to understand the disorder (Caicedo, Interview). Access to medicine is inextricably linked not only to money and income, but also to level of education. One example that a subject at La Joya described clearly depicts these intersections. When discussing her plans for that day, she told me she was going to accompany a mother to the pharmacy. She explained that she often goes to pharmacies with families to ensure that they receive the correct medications. Many parents have a primary education or lower level of education and are functionally illiterate, and therefore are not able to read the labels on the medication bottles. Thus, they may not actually know what medications they are giving to their child. The participant explained that in these lower income areas, it is not uncommon for pharmacies to make mistakes in regards to dispensing medications. This poses a serious problem for those who cannot read the labels. Not only this, but these parents are also unable to read the instructions about when to give their child the medication, how often, and in what quantities. The social worker at La Joya described a specific situation in which a parent was administering aspirin to their child who had epilepsy. Due to the mother's illiteracy, she was unaware that she was giving her child the incorrect medicine and could potentially be putting her at risk (Bolaños, Interview).

Education plays a vital role not only in how family members treat their children with disabilities, but also how community members that may not consistently interact with special needs children perceive them. Participants at both sites expressed their belief that the best way to educate others about disability is exposure. One participant at La Joya described a scenario in which she believes a lack of exposure was the root cause of discriminatory action toward a disabled child: “The children from one of the classes at La Joya went on a day trip to the city center [Otavalo] to the movie theatre for a show. One teacher, one aide and I accompanied them for the trip. As they were settling in to their seats and waiting for the movie to begin, one child began to stir, moving backward and forward, yelling and acting out. Someone in the theatre approached me and angrily told me to hit the child to make them stop yelling” (Bolaños, Interview). The participant explained that she believed this type of comment represents ignorance about disability in the community, and that it is this lack of education about disability that builds negative constructs. All participants at the case study site at La Joya expressed the belief that the “level of understanding in Ecuadorian society is very low” (Esparza, Interview). Every subject described an encounter or experience with an individual who held negatively valenced views about children with disabilities and many attributed this to a low level of awareness, education or exposure to disability in the community. However, some also expressed their view that although compared to many western countries, level of understanding in Ecuador is lower, due to recent government programs and legal changes, people are becoming increasingly educated about disability. In comparison with other countries in Latin America, Ecuador may in fact be setting an example of how to better include and treat individuals with disabilities in societies. This paradox exemplifies the importance of context in defining perceptions of disability.

One subject from the Otavalo site described the recent transition he experienced in Ecuador. “Six years ago, they [people with disabilities] were without medicine, and without help. They didn’t leave to enter society and were invisible. People thought that it [disability] was contagious. I would hear things like ‘don’t touch a person with autism because you could get it’ or ‘having a child with disabilities will make you stupid or slow’ People didn’t have a real understanding of disability. Now, I hear less of these comments. There are more campaigns for health and education here [in Ecuador]. We need to continue making these changes. One of the pathways for this is education” (Caicedo, Interview).

The overall education levels of communities can be understood by statistical measurements. One example is that in the *campo*, the rural region of Ecuador, around 35% of men and 53% of women are functionally illiterate (Kress). This implies that approximately one third of this male population and more than half of the female population has received no or minimal primary education. Without access to formal educational settings, people often lack exposure to peers with disabilities and also do not have settings in which they are able to learn about disability as a construct. In Otavalo, some of the indigenous community members face challenges not only with Spanish literacy, but also with speech and understanding. Because the many natives speak Kichwa, parents who did not attend schools with Spanish programs along with those who received no schooling, often faced communication barriers in regard to comprehension of knowledge about their child’s disability, instructions concerning medication and therapy and other information. One subject at La Joya described that sometimes parents act as though they understand conversations with her, but in reality they nod in agreement, even if they are unsure of what is being said. This subject presumed that this might be due to shame or embarrassment (Bolaños, Interview). Similarly, all subjects at La Joya identified difficulties of

communicating with parents, siblings and other family members. This was also seen when teachers sent home journals updating parents on their children's learning, behavior and progress. Often times, these journals were not returned, and participants speculated a variety of reasons for this including inability to read and write in Spanish. At Shalva, the spoken and written language used is Hebrew and the children's parents are either native Hebrew speakers or fluent after *making aliyah*, or moving to Israel. Therefore, the issues experienced due to language differences between parents and La Joya staff members are not as commonly seen at the site in Jerusalem. At Shalva, teachers also use the format of daily or weekly journal communication to contact parents and update them on their children's progress, challenges and education. The teachers and therapists at Shalva reported success in using this channel of communication to update parents as well as hear parent's feedback and described it positively and as an open-line of communication encouraging an inclusive approach of children's development (Anonymous Participant 2, Interview). The comparatively higher rates of literacy and education of the population at Shalva allow for use of such methods to discuss child learning and progress. In order to provide culturally competent care and treatment, centers and organizations for children with disabilities need to take into account these demographic variables and cultural norms regarding education.

V. Access to Therapy

Another area in which access to resources is influential in the treatment of children with disabilities is therapy. In different parts of the world, certain types of therapy are more commonly used while others may not be used at all. Along with this, access to therapy services is restricted in many areas. This may be attributed to a lack of training, high expense of services or shortage of therapists. As previously discussed, Otavalo has only one center for children combining both education and therapy. Although there are some other options for therapy

services in the area, these are scarce and the majority of the population does not have financial resources necessary to attain these therapies for their children. One subject estimated that there were only two centers providing therapy similar to La Joya in the province of Imbabura (Esparza, Interview). Often times, access to therapy for children is also limited by age. La Joya provides therapeutic services to babies and children up to age twelve, and after this, children are no longer able to benefit from the services at the center, and families are faced with the challenge of finding continued support for their children.

At Shalva, there are several specific types of therapy services available in addition to speech and physical, including hydrotherapy, music therapy, art therapy, computer therapy, animal therapy, art therapy and a snoezelen room. The snoezelen room is particularly unique in that it involves multisensory therapy techniques and focuses on relaxation and improving sensory-motor functions. The presence of these facilities and professionals to conduct these therapeutic services at Shalva indicate the wealth of resources that the center has available to children with disabilities.

In this case, the difference between access to therapy services at the Ecuador site and the Israel site is drastic. Although this result may not be generalizable to each of these countries, sentiment among staff members at each site reflects this difference. At La Joya, when participants were asked about availability of therapy to children with disabilities, the response was that there is a minimal level of access throughout the country and particularly for the indigenous community. One subject attributed this to be due not only to low incomes and inability to pay for services, but also lack of transportation. Because many of the families of the children at the centers live in small villages in the mountains, there are no busses that circulate these areas and many people do not use cars. At Shalva, the therapists were more optimistic

about opportunities for children to receive and maintain therapy. When discussing the availability of therapy with teachers at the center, they expressed their confidence that generally, children in Israel have sufficient opportunities to go to a multitude of therapy services (Anonymous Participants 3 and 4, Interviews). One social worker described that animal therapy has become extremely popular in Israel, for example, horseback riding for children with autism (Shemesh, Interview).

VI. Within-Group Differences

Participants also pointed out within-group differences between Orthodox and secular families in Israel. One social worker believed that ensuring that a child with disability from an ultra-Orthodox family consistently attends recommended and/or needed therapeutic sessions is sometimes difficult (Anonymous Participant 2, Interview). The subject attributed this to the large number of children in many of these families possibly contributing to a lack of attention given to the child with a disability. This example represents within-group differences in Israel. In Israel, the Orthodox population has a significantly higher average birthrate than secular Jewish families. Often, Orthodox Jews live in isolated communities. Some of the Orthodox-identifying participants in this research had not ever traveled to Tel Aviv, Israel's largest and most modern city located only about an hour and a half away from their home in Jerusalem. This factor combined with having lower average incomes to support on average larger families may contribute to having a lower level of knowledge and access to resources across many areas including therapy services.

Similarly, these within culture differences were observed in the study of Otavalo, Ecuador between indigenous and mestiza groups. Indigenous families on average were larger than non-indigenous, and the indigenous families were more likely to live in the mountains,

isolated from medical and treatment resources, including therapy services. While there are many differences between the Orthodox Jewish population and indigenous groups in the highlands of Ecuador, a theme across both case study sites was that these groups on average had lower income levels, lived in more isolated communities, and had larger families. All of these factors play a role in influencing the ways in which children with disabilities are treated, and the ways in which families and communities view disability. In addition, in comparison to mestiza and secular groups (at each respective site), indigenous and Orthodox groups had more collectivist cultures. While the overall cultural structures and norms in both Ecuador and Israel are more interdependent and value cohesion over individualism in comparison to the western world, these groups in particular conform to these collectivist norms and these values play a major role in their lives.

VII. Culture Specific Issues

While all of the aforementioned categories influence how children with disabilities are treated and viewed globally, within each distinct culture there are particular issues that arise that may not be very unique to that specific place. These may be due to differences in key societal structures. One example of this is in Israel, the norm for the majority of the population is to enter the army at the age of eighteen. Because there is a mandatory draft, teenagers from across many parts of Israeli society ranging from Israeli-Arabs and Bedouins to secular Jews and even to some religious Jews, serve in the Israeli Defense Forces. This time of service is a critical component of Israeli culture and society. It is an important step in the lives of Israeli youth and is a formative experience. Often times, one's position in the army impacts their future opportunities in regards to work and status. Many of the country's leaders served as paratroopers in the Israeli Defense Force or in other highly recognized army troops. Thus, having an admirable position in

the army opens doors for people in Israeli society, allowing them access to opportunities they may not have had otherwise. For people with disabilities, serving in the Israeli Defense Force poses many challenges. Firstly, this population is legally exempt from army service. Thus, there is an unequal requirement that able-bodied people must serve their country while those with disabilities are excused. People with developmental and physical disabilities do not have equal opportunities to serve in the army; therefore they cannot access many of the opportunities and benefits that come with and as a result of army service.

One young woman, named Dina Elaiv, writes a blog on the Israeli Defense Force website detailing her experiences as a soldier with cerebral palsy. She describes her experience saying that “The day I got the letter saying that I need to report for the IDF’s initial tests and medical exams was one of the most exciting days of my life. But immediately after arriving at the base, I was told that I was exempt due to medical reasons. That wasn’t what I wanted to hear. I wanted to serve” (Elaiv). This article represents the struggle that people with disabilities face in gaining access to this crucial Israeli experience. Elaiv expresses the discontent of her family and friends, her challenges with transportation due to a lack of wheelchair ramps, and the motivation needed to finally convince Israeli Defense Force leaders that she could serve.

While serving in the IDF is an important stepping-stone for many people in Israeli society, most Orthodox Israeli Jews do not serve in the army. Thus, people with disabilities in these populations, including that of Har Nof where Shalva is located, are not necessarily limited in their communities by impeded access to the army. However, males with cognitive and physical disabilities are often limited in entering the most prestigious *yeshivot*, Jewish institutes of learning in which men study sacred, religious texts. Similarly to the challenges faced with

gaining a position in the army, having unequal access to studying in the *yeshivot* for men limits access to opportunities of reaching the top of social hierarchy in this community.

VIII. Conclusion

Access to resources whether they are educational, economic, or medical greatly influence how children with disabilities are treated, cared for, and viewed. Along with this, ability to access all of these resources is intertwined. Often times, for example, a lack of financial resources contributes to fewer educational opportunities and the inability to pay for private medical services, pharmaceuticals or treatment. Because participants often mentioned these factors as resources and differences in the lack or availability of them, it is important to examine perceptions and treatment through this lens. In addition, it is critical to consider not only between-group and within-group differences, but also to understand relevance of individual differences. This research has limited application and reflects the views of individuals who have opinions and biases. The qualitative data from these studies is supplemented by existing literature and together these components provide us with a framework for understanding that access to resources can be formative in effecting people's behaviors and opinions.

CHAPTER 2: EDUCATIONAL AND LEGAL STRUCTURES

I. Introduction

The educational and legal structures in place across societies are critical determinants of how individuals construct their views and treat other citizens. Within the field of disability, advocates and leaders have utilized pathways of education and political reforms to progress forward and make major changes in societal structures. Such reforms and systems have had and continue to have major implications in the lives of children with disabilities and the ways in which the overall population views and treats these individuals and communities. This chapter will explore how laws and political systems in addition to educational frameworks influence treatment and views of disability in Otavalo, Ecuador and Jerusalem, Israel. Like the previous chapter, the data on these topics is drawn from behavioral observations, conversations with subjects and existing literature and data. Subjects often brought up political reforms, laws, government programs, schools, classroom structures and educational options in the context of answering questions about and discussing disability in their societies, countries, cultures and communities.

According to the U.N. Overview of International Legal Frameworks for Disability Legislation “effects of disability-based discrimination have been particularly severe in fields such as education, employment, housing, transport, cultural life and access to public places and services” (United Nations Enable). This statement touches upon all of society’s resources, showing how discrimination against people with disabilities can influence every domain of life. The U.N. and state governing bodies have made strides, particularly in recent years to reduce this discrimination by writing legislation that prevents discriminatory action across areas of life including work, school, human rights, and more. In addition, discriminatory practices that impact

people with special needs are often “a result of social and cultural norms that have been institutionalized by law” (United Nations Enable). Today, law is increasingly used as a tool to pave the way in altering perceptions and views of disability, in addition to other issues. International law plays an important role in setting the stage for such changes, however legislation at the level of each individual nation and country are what influence specific value changes and altering perceptions on the community level. Participants at each site noted changing legislation and policy in their explanations of how people viewed disability

II. History of Disability Law

When examining legal structures in relation to disability internationally, it is critical to study the history of disability legislation in each country. The original model for providing assistance to people with disabilities in Ecuador was based upon charity programs beginning in the 1950s, through the work of families and non-governmental organizations. Over time, this framework has shifted focus from giving charity to fighting for the rights of people with disabilities. In the 1970s, government agencies became leaders in providing programs supporting the health, education and equal status of people with disabilities. In the 1990s, the government created *CONADIS: Consejo Nacional De Igualdad de Discapacidades* (The National Council on Disability Equality). Today, this council continues to be a leader in progressing the rights and treatment of people with disabilities in Ecuador. Ecuador’s government is seen as a leader of Latin America in terms of developing and implementing legislation that supports people with disabilities across domains. One subject at La Joya stated, “we [Ecuador] are initiating reforms, programs and laws that will encourage other countries surrounding us to follow” (Anonymous Participant 5, Interview). Much of this is based upon the past vice president of Ecuador, Lenin Moreno, and the programs he developed and implemented to support individuals, particularly

children with disabilities. Subjects at La Joya believed because a charismatic national leader was in support of such changes, this influence trickled down and played a role in changing previous notions of disability across a variety of diverse groups in the country. While Ecuador's legal and political systems may be paving the way in regard to bettering the quality of life for people with disabilities, this "markedly contrasts with the general social and economic development of the country" (International Disability Rights Monitor Publications – Ecuador 2004). This example depicts that even in less developed areas of the world that may be struggling with socioeconomic conflicts and difficulties, it is still possible to lay foundations for and work toward development of human, education, employment and other rights for people with disabilities through legal systems and improvements.

Disability rights are discussed both in Ecuador's constitution and in further depth in additional legislation. In an article "U.N. Salutes Ecuador for Promoting Rights of Disabled People: Ecuador Wins FDR International Disability Award", previous U.N. Secretary General Kofi Annan expressed his praise for Ecuador being one of the first and only countries in the world, not just Latin America, to include disability rights in its constitution and then to continue to provide supplementary legal structures. The word disability/disabilities is found forty times throughout the Ecuadorian constitution. Article 47 states that "The State shall guarantee disability prevention policies, and along with society and the family, it shall ensure equal opportunities for persons with disabilities and their social integration," proceeding to list the rights of people with disabilities, including equal opportunity in working conditions, guaranteed education in the public school system, free psychological care, elimination of physical barriers (for example, providing wheel chair ramps), and developing specialized programs for care that "promote their autonomy and reduce their dependence." In addition, people with disabilities are

included in the section on Rights to Freedom. Another unique aspect of the Ecuadorian constitution requires the creation of National Councils on Equality for a variety of groups including children/adolescents, persons with disabilities, women, indigenous peoples and nations, Afro-Ecuadorians and coastal back country populations. Children with disabilities, particularly those at La Joya who were predominantly indigenous, fall into multiple groups that these national councils strive to protect. This illustrates the overlap of disability law with many other aspects of the legal structure, once again demonstrating that each of these factors are inextricably linked and in order to gain an extensive understanding we must examine these constructs in relation to one another.

In comparison to participants at the Jerusalem site, those in Otavalo cited more often the areas of law, political leaders, special reforms, programs and platforms as factors in understanding disability in the country's context. The role of the government played a major influence in perceptions of the people and the sentiment toward disability. This heightened knowledge of and belief that the law plays a large role in defining disability in Ecuador may be attributed to the work of one of the country's key leaders, previous vice president Lenin Moreno. One of the first topics mentioned by multiple participants in Otavalo was the labor reform law implemented by Moreno that requires hiring quotas for public and private companies for people with disabilities. This regulation mandates that four percent of nation's workforce should be composed of people with disabilities. All of the subjects at the site were aware of this law and acknowledged it as important and beneficial. This statement of inclusion represents a unique effort in the context of Latin America to ensure that people with disabilities not only do not face discrimination, but in addition are required to be included in workforce policies according to national law.

While many legal documents depict the Ecuadorian government's dedication to equality and rights for people with disabilities, some subjects at La Joya believed that Ecuadorian society still has a long way to go in regard to making actual improvements in the lives of people with disabilities. Subjects at La Joya noted examples in which although disability laws exist, they are not being enforced properly. For example, one law noted by staff members at La Joya was the Regulation on the Registration of People with Disabilities. This law requires individuals, including children, to have a disability registration card. The purpose of this is to then provide them with benefits in society ranging from health care, to education, to tax exemptions later on in life. At La Joya, every child has an identification card on file, stating their basic information and type of disability. The majority of the children at La Joya are registered as having a physical disability, including those who also have cognitive and developmental impairments. One therapist at La Joya explained that doctors often "fly through" these disability evaluations, not taking the proper amount of time and care to complete them thoroughly (Anonymous Participant 5, Interview). In addition, doctors rate the severity of the disability on a scale of 0-100%, however this scale is somewhat subjective and leaves much of the decision-making up to the individual doctor. In some cases, children receive inadequate identification, are mis-identified as not having a disability when in reality they may, or as having the incorrect type of disability. Because benefits are provided to individuals, particularly children, on the basis of their status according to the severity and type of disability on their registration card, these problems can challenge the legal structures that are put in place. The legal system depends not only upon the development, creation and institution of just laws, but also upon enforcement. In order to ensure that these laws are enforced, societies must rely on other institutionalized structures as well, in this case, the medical system. It is up to doctors and health care professionals to conduct proper

evaluations so that individuals with disabilities can access what they are legally promised as citizens of Ecuador. In addition, there still remain some laws that “contain discriminatory language and negatively impact the rights of people with disabilities.” For example, section 102 of the Civil Code states that people who are blind, mute or “insane” are forbidden from acting as witnesses to marriage, signing a will, or holding legal guardianship (International Disability Rights Monitor Publications – Ecuador 2004).

In the state of Israel, a written constitution does not exist. While there are basic foundational laws that create a government system, called *hukei hayesud* in Hebrew, these are spread across different areas of law rather than all found in one document. This difference in legal structure makes it impossible to compare statistical measures including how many times the word disability is mentioned in each nation’s constitution; this demonstrates the importance of noting these differences and the distinctive characteristics of each system that make it difficult to draw comparisons.

The major piece of legislation on disability rights is modeled after the Americans with Disabilities Act, created in 1998 and titled the Equal Rights for Persons with Disabilities Law (also known as the “1998 Act”). This legislation represents the first successful attempt to develop a comprehensive set of laws to protect the rights of individuals with disabilities. It covers areas including: defining disability, establishing a special commission for equal rights, employment, public services, transportation and accommodations and provides guidelines for enforcement. The law defines a person with disabilities as “a person with a permanent or temporary physical, mental, or intellectual – including a cognitive – impairment, due to which his functions are substantively restricted in one or more main spheres of life” (International Disability Rights Monitor Publications – Compendium – Israel). This definition includes both

the medical and social components of having a disability. Leading up to the development and implementation of this legislation, there were three major laws for people with disabilities including the Veterans with Disabilities Law in 1959, The Work-Related Disability Law of 1954, and the General Disability Law of 1975. Each of these “reflects the social welfare ideology, providing cash benefits on the basis of proven eligibility and focusing on the individual” (Rimmerman). This focus is a reflection of the medical model, in which the emphasis of disability is placed on the individual rather than on the surrounding environmental and social world. The creation of the 1998 Act can be pinpointed as the shift in legal definitions of disability in Israel from medical to social and environmental. Rather than compensating individuals who meet medical definitions of disability, this act focuses upon transforming social and environmental opportunities and minimizing discrimination. The act consists of four key sections. The first section, fundamental principles, focuses on equal rights to participate in society and across all domains. This involves the individual’s right to make decisions about their own lives and the importance of their ability to express these rights in an integrated society rather than in separate realms. The next section contains anti-discrimination policies for the workplace and provides rules for provision of modifications for employees with disabilities. In addition, this section of the Equal Rights for People with Disabilities Law states that employers should “take action to promote their [people with disabilities] proper representation, including the making of adjustments.” This standard for ensuring representation is found in Ecuadorian legislation as well, and depicts the changing global emphasis on integration and representation in the workplace. The third main point this law makes pays unique attention to public transportation. The fourth and final key aspect of the Equal Rights for People with Disabilities Law is creating an equal rights commission, which is an “independent body financed by the government and

charged with the mission of advancing the rights of people with disabilities and enforcing the Equal Rights Law” (Rimmerman).

While this new set of laws represents the Israeli government’s increasing ideological commitment to supporting and ensuring people with disabilities have equal human rights, according to some researchers it has proven difficult to implement and its impact has been less than expected. Similarly to subjects at La Joya, those at Shalva also shared their concern about implementation of disability rights legislation, particularly in the case of children. One Israeli social worker stated “the government has been making an effort in recent years to integrate people with disabilities into society and end discrimination, but there are many difficulties that we must overcome to make sure these laws are followed” (Shemesh, Interview). This may be due to a multitude of factors, one being the “piecemeal approach” to policy-making, which Rimmerman describes as “when the government is spurred to action as a result of pressure and circumstances rather than out of any desire to construct and implement a cogent and carefully planned strategy” This falls in the middle of a continuum of disability policy models ranging from the negative policy model in which countries deny any human rights to people with disabilities to the social/rights-based policy model in which the emphasis is taken off of the individual and placed onto society. When policy-makers are driven to create disability legislation due to these temporary pressures and situational factors rather than making consistent strides to work towards disability rights, there is a fundamental problem in motivation that subsequently influences whether or not the next necessary steps will take place. Thus, Rimmerman suggests that policy-makers are critical in not only creating purposeful and meaningful national disability law, but also ensuring that these laws are implemented.

The important function that policy leaders play is also clear in Ecuador, in the case of Lenin Moreno. This case however shows the positive role that consistent and devoted policy makers can serve. Participants at La Joya continually spoke about the case of their vice president, one stating “the idea that the vice president is in a wheelchair, that someone with a disability can achieve a position of power, is a step forward” (Caicedo, Interview). Unlike the policy-makers described by Rimmerman, who overall experience great social distance with people who have disabilities, Moreno is deeply connected with the disabled population, having a physical impairment himself. Thus, he has consistently prioritized disability legislation and programs throughout his term. One example of programs successfully executed in Ecuador is the development of organizations that provide free artificial limbs to Ecuadorians with disabilities living in poverty. At La Joya, one of the children received a prosthetic leg through an organization called *Fundacion Protesis Para La Vida* (Prosthetics for Life Foundation), a joint project funded by the U.S. Rotary Club in collaboration with the Ecuadorian government under Lenin Moreno. This particular organization emphasizes that the program is staffed and run by Ecuadorians, so that the care is culturally relevant and sensitive to the population they provide for. The Prosthetics for Life foundation uses a variety of materials and scraps they receive from donations to create prosthetics and braces for children with disabilities. Subjects stated that as a key political leader, Moreno played a critical role in Ecuadorian government support, creation and growth of collaborative projects such as these. Now, many programs have their roots in government and national support and operations, rather than depending upon international aid. Such examples are part of a large initiative, which is also an amendment to the Ecuadorian constitution added in 2008, known as *Ecuador Sin Barreras* (Ecuador Without Barriers). This initiative, led by Moreno, helped to develop jobs for people with disabilities, provided funding to

increase access to public buildings and opened training and rehabilitation centers for people with disabilities (such as La Joya). This initiative also represents an attempt to begin to provide different services to people with different disabilities; demonstrating an understanding for the difference between intellectual and physical disability in legal documentation. In addition, Ecuador Without Barriers implements support for families of children and adults with disabilities, providing a monthly stipend of \$240 to caretakers of people, especially children with disabilities (2010 Human Rights Report: Ecuador). Moreno was recognized internationally through receiving the Nobel Peace Prize in honor of his commitment to people with physical and mental disabilities. The case study of Ecuador represents a clear case in which an individual, charismatic political leader is able to influence the sentiment of a nation.

Overall, the different legal and political structures, attitudes and programs play a major influence in the daily lives of people with disabilities at both case study sites. Both places have experienced recent shifts in framing disability from medical to social, a critical step in continuing to work for inclusion and acceptance of people with disabilities. In addition, subjects at both case studies mentioned policy-related subjects and individuals with legislative power as playing an indirect role in the lives of the children at their centers. Along with noting legal systems as important in the way society looks at and understands disability in each community, participants also often discussed educational structures and how these influence both children with disabilities and the way that others view them.

III. Education Structures

Our education systems provide context for children to interact through formal learning and peer-to-peer experiences. “The way that children are trained and schooled is a crucial demonstration of the way they are perceived and treated in a given society” (Winzer xi). The

history of special education, including children with mental and physical disabilities in schools, is linked to changes in legal structures, as discussed previously. In order to develop special education systems, people are dependent upon legislation to mandate and enforce regulations and develop systematic changes.

In Israel, there are four main sections of the education system, which are also representative of Israeli cultural and religious groups. These include Jewish Secular, Jewish Religious, Non-Jewish (Israeli-Palestinian) and Independent (Jewish Ultra-Orthodox). Because, as previously mentioned, Israel has no legal constitution it has relied upon other legislation to provide services such as people with disabilities. One key piece of legislation relevant to inclusion of people with disabilities in the nation's educational framework is the Special Education Law of 1998 (SEL). This law "reveals a basic conceptualization among Israeli law-makers at the time as it advocates for a segregationist and categorical perception of service provision" (Meadan & Gumpel 16). Before the execution of this law, there were virtually no regulations on education and learning for children with disabilities, and procedures for enrolling students with disabilities in schools were "based on an informal form of negotiation among the educational system, the child's family, and the Ministry of Education and Culture" (Meadan & Gumbel 16). This law provides definitions of disability and special needs, and defines special education. It also outlines a specific process that all children with special needs must go through in order to receive special education services. Children must be assessed by a licensed school psychologist and considered eligible to receive special education. After this, they are referred to a local Placement Committee, which then determines their placement in a school. These committees are comprised of a diverse range of individuals including: a local education representative, Ministry of Education supervisors, an educational psychologist, pediatrician, social worker, and someone

from the National Special Education Parent Organization. This composition brings people from a wide variety of professions together to provide a result that represents an inclusive point of view from a family, health, and educational perspective. However, this group does not include the parents and caretakers of the child themselves, thus they may be missing key information about the child that would influence their status. This is one crucial criticism of the law, according to Meadan and Gumbel. There are two main types of decisions that these committees can make: special education setting or a general education setting. However, as one subject at the site in Israel also pointed out “the system lacks special education classrooms within general education settings... the choice is either for children with disabilities to go to schools exclusively meant for special needs, or for them to struggle in typical schools” (Anonymous Participant 1, Interview).

This lack of integration of special education and inclusion is not solely a challenge faced in Israel. Subjects in Ecuador also voiced their concerns about this issue; institutions for solely children with disabilities exist, as do normal schools, however the combination of special education elements in normal schools is lacking. In Ecuador, the high poverty levels amongst families with special needs children, particularly in the indigenous community, are a barrier for entry of children with disabilities into any sort of education system. While there is a national legal framework for inclusion of children with disabilities into educational structures, this is challenging to implement in rural and resource-poor areas. La Joya is one of very few centers in its region to provide special education services. Even at La Joya, many subjects raised concerns about the educational futures of the children currently attending the center. Because the center has resources to support children only up to the age of twelve, after reaching this age, students and their families must make decisions about next steps. In Otavalo, because there are few options for special needs programs, especially for teenage students, most families are faced with

the decision of whether or not they should send their child to a typical school. The social worker and psychologist at La Joya support families and help evaluate children at the center to determine whether or not they recommend entry into a typical school.

This segregation between regular and special education not only impacts children and families with disabilities themselves, but it also raises issues about how people perceive disability in each community. Because there are very few children with disabilities in typical schools, particularly in the elementary years, most non-disabled children have very limited, if any, experience with children with special needs. When children with special needs and non-disabled children are placed in learning settings in which both populations receive the necessary, individualized support, these peer-relationships allow non-disabled students to develop positive social constructions of disability. Because this does not regularly occur in so many places around the world, including both Ecuador and Israel, children may be more likely to develop negative views of disability rooted in this lack of interaction and first-hand opportunities to learn about disability.

In many countries that are less developed, people with disabilities may be completely excluded from any educational settings. For example, in Ecuador as of 2004, almost 40% of the disabled population received no education whatsoever. About 42% of this population has completed only a primary education, and only about 10.5% have completed secondary school (International Disability Rights Monitor Publications – Ecuador 2004). The case study of La Joya reflects these numbers. According to staff members at La Joya, while centers for primary care of children with disabilities exist, there are far fewer options for children with special needs to receive a secondary education.

The 2013 State of the World's Children official report states "children with disabilities are disproportionately denied their right to education, which undermines their ability to enjoy the full rights of citizenship, find gainful employment and take up valued roles in society" (UNICEF, 8). The report defines inclusive education as not separating children with disabilities in distinct schools but rather "providing meaningful learning opportunities to all students within the regular system" (UNICEF 8). There are several components of this meaningful learning opportunity, including individual supports and a child-centered curriculum that encompasses the wide range of children across society. Often times, inclusive education of children with disabilities must begin in nurturing homes in which families make strides to foster interactions between the child with a disability and others in the community. Not only will this better the life of the child his or herself, it will also contribute to increasing community exposure of children with disabilities; this may in turn reduce stigmatization and negative perceptions. The idea of inclusive education begins with this familial and community support at the child's earliest stages of life, and transfers into the importance of committed teachers with appropriate training and a positive school environment. This definition of inclusive education places the responsibility on societal frameworks rather than individuals, in line with the social model of disability. The role of families, teachers, school systems, laws and other outside resources is crucial in creating inclusive and integrated education environments. The report states that children with disabilities "sit uncomfortably within existing structures and systems of education" (UNICEF 10). This idea encompasses many discussions with subjects at both case study sites. Because inclusive education is still a goal and work in progress globally, many children find themselves in this limbo, either separated or lost without the necessary supports in typical schools. "It isn't enough just to let children with disabilities attend normal schools. These schools need special designs

and specific curriculums. The teachers need to be trained and open-minded” (Anonymous Participant 5, Interview).

These educational challenges are linked with many other related societal problems including gender inequalities, health problems and employment. The research and explanations provided throughout this chapter attempt to provide a glimpse of educational and legal frameworks in Ecuador and Israel and explain how these fit into today’s global structures. It is critical to understand that attitudinal change and the ways in which people perceive children with disabilities is deeply rooted in our societal configurations. While education and legal systems played a large role in discussions with people interacting with children with disabilities in Ecuador and Israel, these are not the only structures influencing perceptions and treatment. Ranging from health care, to the economy, to media and to employment, all of our current global social systems serve both as barriers and potential pathways to inclusion. Our policy leaders and educators are key players in transforming these barriers into activist pathways. In addition, these structures are responsible for forming much of public opinion and societal norms; therefore if we look to them to create more inclusive environments, this will decrease negative perceptions of disability and increase the ways in which we positively define disability in our cultures. From reforms such as Ecuador Without Barriers to Israeli creation of legislation laying the foundation for disability rights, political and educational frameworks in both Ecuador and Israel are beginning to transform community perceptions of disability and opportunities for children with disabilities. However, this will be a lengthy process and it only begins with such structural changes. At both La Joya and Shalva, staff members discussed the importance of implementation and exposure. Changing treatment and views of disability goes beyond the creation of laws and ideas about inclusive education; it requires implementation and awareness.

CHAPTER 3: ETHNICITY AND RELIGION

I. Introduction

Religious beliefs, traditions and norms have forever defined the ways in which people function and think. Ethnic affiliation and status have additionally played a constant role in the labeling and placement of individuals in our society. These factors continue to be major influences in our behaviors, views and interactions. Religious and ethnic beliefs and norms intersect with disability in many ways. From sacred texts to creation of community-wide values, religion discusses and provides many outlooks on disability in the past. These representations are critical in defining the ways in which populations treat individuals with disabilities in the present and future. Because almost eighty-five percent of humans have some religious affiliation (Hackett & Grim), religion is and will likely continue to be a critical part of shaping perceptions and learning across the lifespan. For many people who are deeply rooted in spiritual faith and beliefs, humanity in itself is defined by religion. “If we are to presume a world of difference, the guidance of our cultural-religious codes provides some blueprint for how to navigate these differences” (Schuelka 501). Religion provides teachings and guidance on how to view differences, including differences in ability, across humanity. Biblical passages are full of stories and words that paradoxically demonstrate both compassion and punishment toward people with disabilities. These allow for the development of different conceptualizations, based upon interpretations. Popularized interpretations are then influential in directly impacting views and, in turn, behaviors.

In our current and past societies, ethnic status often determines how we categorize and treat people. The realities of ethnic labeling reflect many underlying problems we have in our society today. Throughout history, ethnic status and differences have served as a justification for

disastrous conflicts, and horrible crimes of atrocity. The notion of white supremacy remains prevalent around the world today, and many ethnic minorities continue to be discriminated against due to their differences in appearance, culture and background. Racial and ethnic tensions in Andean Ecuador run high, with both white and indigenous communities living together. Although subjects at La Joya noted that tensions were beginning to decrease, many examples of ethnic discrimination were observed throughout the research and remain prevalent in the culture. Subjects at La Joya greatly emphasized the differences between indigenous and white perceptions of disability, and cited ethnicity/race as a factor in affecting how people treat disability.

Participants at both La Joya and Shalva discussed the influence that both religion and ethnic status played in each culture, and how these constructs intertwined with definitions of disability. In addition, religious affiliation and ethnicity are linked with many other factors discussed in previous chapters. For example, at the case study site in Ecuador, the children of indigenous ethnic backgrounds came from predominantly lower-income and more distant homes in comparison with the white children enrolled at the center. Thus, it may be difficult to separate whether or not conclusions about how these families and individuals treat disability are rooted in their ethnic culture or factors associated with a low level of access to resources. This represents the importance of understanding how attitudes are shaped by a combination of factors. It is near impossible to separate each of these threads, thus it is difficult to pinpoint whether it is religion, ethnicity, education, legal structures, access to resources, or the multitude of other factors in society that shape how children with disabilities are viewed and treated. Each of these aspects provides an important lens to consider.

II. Judaic Conceptualizations of Disability

Subjects at Shalva, in Jerusalem, are predominantly Orthodox Jews. Specifically, many children, families and staff members at the center are part of a sect of Orthodox Judaism, called Haredim. Haredim strictly follow religious laws and pray many times throughout the day. Unlike secular Jews living in Israel, Haredim live according to tradition rather than embracing modern ways of life. Therefore, many members of this community live in isolated communities, do not go to the Israeli army, and undertake the intense study of Judaism in *yeshivot*, institutes of Talmudic learning and education. The participants at Shalva emphasized an unwavering belief in the importance of God in their lives, and in the lives of families and children with disabilities. Religious perceptions and understandings played a crucial role in discussions revolving around definitions of a child's disability and disability in society.

The story of Shalva's founding demonstrates the essentiality of religion in the purpose and work of the center. In 1990, an Orthodox Jewish couple, Malki and Kalman Samuels, created the center and organization. In 1977, the Samuels had a baby, named Yossi, who was born healthy. During a routine vaccination in Israel, around two hundred babies were given a contaminated shot, and Yossi was one of these children. While many of the other children affected by the vaccine died, Yossi survived, but was left blind, deaf and hyperactive. "For eight years, Yossi lived in a closed world with no one able to penetrate his bubble" (Anonymous Participant 1, Interview). His parents searched for help in Israel, and ultimately they heard from doctors and specialists that he was doomed. Because they weren't ready to give up hope yet, they traveled to the United States to seek medical support, and once again, received only bad news about their child's inability to survive and function in the future. Feeling lost and confused, they returned to Israel and met a teacher who was able to help Yossi. She taught him how to use non-verbal communication to connect with others. Malki refused to place Yossi in a hospital or

institution, and with her dedication and persistence she was able to help him find the supports he needed. Because of her experience, Malki made vow and promise to God that if He helped her son, she would in turn dedicate her life to helping other children with special needs and their families. Through this narrative, it is clear that the foundation, goals and mission of Shalva are deeply rooted in this spiritual lifestyle and the connection with the sacred.

According to the literature on Judaism and disability, the Jewish God deems all people of equal worth and places equal value on all lives. “This is not contingent on good health or an able body. Therefore, Judaism rejects totally the notion that some lives are not worth living” (Gaventa 117). This perspective includes all people and all bodies – abled or disabled. “All life is of the utmost value, and this is so whether or not disability is involved. Judaism recognizes that all people are of equal, infinite and ultimate value, even though people vary considerably in ability, personality, shape and size” (Gaventa 118). These notions of the Jewish God’s demands of equality regardless of ability and the immense value placed on human life are representative of the founding of Shalva. The first objective of the center is: “To support the inclusion of individuals from birth to young adulthood with intellectual and physical disabilities...” (Shalva: The Association for Mentally and Physically Challenged Children).

Daily occurrences at Shalva also re-emphasize the importance of religion in shaping interactions with children with disabilities. One observation from the case study is an activity the children engaged in at the center daily; each morning in the classroom, teachers played an audiotape of a children’s song and danced around the room and sang with the children. The lyrics of this song (translated) are: “Two legs, two legs, a gift from the heavens. With two legs, two legs – what can we do? We can walk; we can run; we can dance.” Teachers explained that for these children, although they had developmental delays, having two legs, two arms, two

hands and two feet is a gift from God. This focus on gratitude to God for all that they have is present throughout each activity, classroom and therapy session at Shalva. Belief in God and Judaic emphasis on human equality and the value of life are the threads running through the organization, keeping its staff members motivated, caring and supportive. These religious views have clear implications for the treatment of children with disabilities. Behavioral observations at Shalva represent the huge amount of care, support and love provided to the children at the center. The staff members treat each child as their own – changing diapers, feeding children, hugging them, rubbing their backs as they fell asleep, holding them, and talking to them calmly when they cried. Likewise, they also disciplined the children as though they were their own. They showed an intricate balance of ensuring that the children felt support and loved but also learned from their challenges and demonstrated appropriate behavior. Ultimately, they served as a second set of parents for these children, going beyond the traditional role of the teacher, therapist or aide. They discussed concerns in the children's personal lives, voiced their opinion when issues arose with treatment and care and spent countless hours going past their duties as teachers. For example, one teacher brought all of her children's hand-me-down clothing to the center to provide for the children whose families faced economic challenges.

While these broad religious views of humanity clearly influence how children with disabilities are treated at Shalva, it is also important to understand specific biblical examples in discussions of theology and disability. Rabbi Elliot Dorff notes "...almost all of the biblical heroes were disabled in some way. Sarah, Rebecca, Rachel and Hannah were all barren for some time in their lives, Isaac and Jacob suffer from blindness in their old age, Jacob was lame for much of his life, and even the greatest biblical hero, Moses suffered from a speech impediment" (Dorff). Dorff contrasts this disabled leadership in Jewish tradition to the physical and mental

perfection of characters in Greek and Roman cultures – “in contrast to the Greek, Roman and American cultures, in Jewish sources, the disabled were construed to be like everyone else and they were often leaders.” (Dorff). While this is true, there are still several limitations and special rules created for people with disabilities according to Jewish law. For example, “blind people should say the blessing before the Shema that praises God for creating light because even though they cannot see the light of day, they benefit from it because others see them and keep them from accidents” (Dorff). The literature on these specificities within the biblical texts is vast. In the context of understanding the influence of religiosity and spirituality on Jewish views of disability, it is necessary to recognize that these special laws and rituals exist. However, the main influences discussed by participants at Shalva included the broader applicability of living in congruence with the values of equality of human life and ensuring the inclusion of people with disabilities. It is due to this belief and emphasis that religiously rooted organizations like Shalva exist. While this research study examines the specific case of Shalva, where religion plays a major role, there are many other organizations, centers, hospitals, and supports for people with disabilities across different religious and cultural groups in Israel. It is likely that of these groups, those who are affiliated with Orthodox Judaism in some way also illustrate the importance of religion in their founding and daily workings. Many groups may be affiliated with other religious, or non-denominational values and beliefs. These organizations also provide critical support to children with disabilities, and further research might inquire differences between non-religious and religious views of children with disabilities in Israel. For many secular Jews, spirituality may minimally influence how disability is defined and treated. In addition, for Christians, Muslims and other religious populations present in the country, differing texts, beliefs, and interpretations foster different interactions with disability. This research focuses on

Judaic conceptions because of their prevalence at the site of study. Religion also intersects with many other arenas of life in Israel. As a country without separation of church and state, Judaism clearly intertwines with the government and legal structures in society. In addition, particularly in the Orthodox community, religion and education go hand in hand. Therefore, it is impossible to separate these factors and they work together to influence treatment of disability and the roles people with disabilities play in society.

III. The Role of Ethnicity in Ecuadorian Notions of Disability

At La Joya, religion and spiritual beliefs also played a role in definitions of disability and treatment of children. Because of the mixed population of mestiza and indigenous groups, there are many spiritual and religious beliefs represented at the center. During a mother's day celebration at the center, mothers sat on a panel and answered a series of questions about having a child with a disability. At this event, one question posed was "What do you do to cope when the situation of having a child with a disability seems too difficult?" In their answers, three of the five mothers referenced spirituality and God, discussing things like praying to God, reminding themselves to have patience, everything is in His hands, He is in control. Other mothers mentioned remembering that this is all a part of God's plan, or that their child is a sign for a better future or plan. The rich mix of sacred indigenous beliefs that remain prevalent in indigenous culture combined with the popularization and spread of Catholicism underlie these spiritual coping mechanisms that mothers describe.

Although religious views were noted in conversations regarding disability, in comparison to the case study site in Israel, religion was discussed less often as a factor influencing the disability framework. Rather, ethnic notions were very regularly cited as important in the shaping of disability in the community. According to the literature, Andean conceptualizations of

the human body are intricately connected with nature and spirituality. “The Andean body, in its ideal, healthy state, reflects a balance between humanity, the environment and the spiritual world” (Cooley 117). Thus, people who have health conditions including disability illustrate an imbalance between these domains. Cooley describes, “The core concept of *debilidad* (weakness, vulnerability) refers to the belief that at any time a human being is vulnerable to natural or supernatural forces intruding into the body, lodging in a particular organ and creating an illness” (Cooley 139). Participants and observations at La Joya recognize this indigenous belief that natural and supernatural forces play a major role in shaping definitions of disability. Staff members at La Joya perceived many differences between mestiza and indigenous interpretations of disability. For example, while mestiza populations focused on medical and biological sources, indigenous individuals were more likely to focus on supernatural and spiritual causes.

The political challenges and ethnic tensions in Ecuador between mestizo and indigenous groups have created a stigma that still lingers in Ecuadorian society today, in which people of indigenous descent are labeled as disadvantaged, subservient, inferior and have even been subject to attempts of ethnic cleansing. By having indigenous bodies rather than white, people were labeled as having a disability. However, in recent years, political mobilization of indigenous groups has contributed to increasing reforms and programs that include the indigenous identity. Along with this increase of the indigenous presence in legal health reforms and implementations has grown the presence and emphasis on disability reform. As previously mentioned, former vice president Lenin Moreno has developed and implemented reforms that strive for better treatment of both indigenous and disabled groups. The co-occurrence and in some circumstances, congruence, of these transformational movements to decrease discrimination against people of indigenous ethnic decent and people with disabilities also points

to a social perception of disability. Definitions are constructed by societal factors including limitations in activities and participation in society due to discrimination on the basis of ethnicity and ability. Through implementation of structural changes and increasingly tolerant practices, we can take strides to develop more inclusive environments and positive perceptions of disability, as it intersects with ethnicity in Ecuador. In order to provide optimal support, care and treatment to indigenous children at La Joya, staff members take measures to attempt to combine indigenous and modern medicine, therapy and education. For example, the curriculum used during my time at the research center was focused upon nature. During one lesson, the teacher brought in a stalk of corn and passed it around to each child, teaching through using a song that describes each part of the plant in both Spanish and Kichwa. Many of these children's families rely upon nature for their livelihood and in addition, the natural environment and earth are core elements in their belief systems. Thus, teaching children about nature and ensuring that some lessons are taught outdoors where they engage in hands-on learning about the crops, the mountains, the sky and bodies of water represents the attempt of La Joya to take into account the ethnic beliefs and views of many families they serve. In this example, the linkages between spirituality, cultural norms and education are also visible. Through inclusion and acceptance of ethnic beliefs, rather than ignorance and minimization, centers for therapy and education like La Joya allow for children with disabilities to learn and be treated in ways that respect their cultural and ethnic values.

IV. Conclusion

This chapter focuses on the influence of Judaic conceptualizations and Andean indigenous beliefs and ethnicity at these two particular case studies. At each site, these were central areas of discussion in the examination of both constructions of what it means to be

disabled and the education and social treatment of children with disabilities. There were many differences between ethnicities and religious groups at each site, however some similarities can be seen in the Orthodox Jewish and indigenous Ecuadorian perceptions of disability. For example, both Orthodox and indigenous participants noted beliefs that God or “the heavens” gave them a child with a disability. In addition to the importance placed on spirituality in understanding disability, these two groups interestingly share some demographic and cultural similarities. Both Orthodox Jewish and indigenous Ecuadorian families tended to be larger in size in comparison to other groups in society. Having large numbers of children in each culture can be tied to other factors – couples may not believe in the use of birth control, or they have not have access to or education on birth control. Both groups also were more likely to live in isolated communities and participate less in modern life. This ranges from engaging in a more limited (or lack of) using technology to wearing customary clothing and attire to engaging in ritual behaviors including prayer, dance and song. These results demonstrate the interconnectedness of our global traditions and sociocultural norms while also depicting the specificities and uniqueness of each distinct culture and individual. Examining these types of samples and learning about similarities and differences can ultimately help us to broaden our perspectives about the constructions of disability. Learning about ethnicities and religions outside of our own can allow us to better understand a family’s story and experience, and become more inclusive and educated therapists, teachers, doctors, aides and citizens.

CONCLUSION: SIGNIFICANCE AND FUTURE RESEARCH

I. Why Understanding Cultural Context Matters

Through the discussion of the insights from La Joya in Ecuador and Shalva in Israel, this thesis has revealed the importance of how cultural context has been an important piece of the changing global definitions of disability from medical to social. Differences across ethnicities, religious groups, languages and cultures are vast, and each of these categories plays a role in how people define both themselves and those around them. By discussing clusters of factors including resource access, legal and educational frameworks, and religion and ethnicity, this research shows that societal factors play a critical role. Cultural contexts shape community norms which influence individual thinking patterns and behaviors. This research shows that cultural context is critical in influencing both structural and individual treatment of disability. At each research site, discussions focused on external influences rather than internal conditions.

There are several important patterns that spanned throughout this work. The first is that individual differences are present throughout. Because the data is qualitative and participants do not equally represent a random sample, it is impossible to generalize what any one research participant contributed to a broader context. Even when cultural norms and life circumstances are similar within groups, individual differences and personal experiences clearly impact a person's belief about disability and contribute to definitions and treatment. Another key pattern is that participants rarely noted the term of a child's medical diagnosis, disability or impairment. Rather, they answered research questions about defining disability through discussing specific examples in their personal experiences that represent how sociocultural influences shape views. Lastly, people in both settings described areas of improvement and recent steps forward for children with disabilities. This depicts that although challenges remain for people who have

disabilities, instrumental attitudinal change combined with structural transformations allow us to advance and progress towards a more inclusive and integrated global environment for people with disabilities. Understanding the role that access to resources, educational and legal systems and religion and ethnicity play in cultural contexts is a key step in both implementing structural changes at institutional levels and advocating for attitudinal developments in individual and community arenas.

II. Future Research

This thesis research represents only a tiny sector of what disability means in other cultures through case study work in Ecuador and in Israel. Future research in this area can investigate if and how the factors addressed in this study play a role in other communities around the world. For example – are there any places where access to resources doesn't influence or shape treatment of children with disabilities? Or, if resource access plays a key role everywhere, how does this role differ? In addition, future work could look specifically at the interaction between factors, to investigate what factors play larger and smaller roles dependent upon cultural context. Researchers can also attempt to draw broader conclusions by conducting data collection with wider and larger subject samples. Even within my work at each setting, there is not enough evidence to draw absolute conclusions about each community. According to the literature, it has proven challenging to study global rates and definitions of disability. This research asserts that this is due to differences in cultures and personal experiences. Environmental factors, such as access to wheelchairs or medical expenses or traditional religious beliefs along with personal individual factors including life experiences impact a person's ability to function and be a contributing member of the community. In order to study global prevalence, we need to take into account that it will not be possible to measure disability according to the same scale in every

country. Rather than focusing on prevalence rates and how to quantify disability in our world, this research suggests we focus our energy on understanding how it is defined according to cultural norms, values, structures and beliefs. Through understanding these constructs, we can develop positive interpretations of disability that lead to a better future for children with special needs. In order to work towards a more inclusive global environment for people with disabilities, we must study and understand how society defines disability. Integration in our schools, inclusion in the workplace and acceptance in the community require activism and advocacy in the political, economic, religious and community spheres. To achieve these goals, researchers must continue to pursue questions about cultural context in shaping definitions and treatment of disability and then share their findings with people who have the ability to make an impact on structural levels. A mural on the wall at La Joya reads “la peor discapacidad es no darnos cuenta que somos iguales” translated to: the worst disability is that we do not realize that we are all equal. This statement perfectly depicts the beauty and importance of this research. It places the responsibility amongst the community and society and takes the blame, shame and limitations of disability off of the individual who has special needs. The study of Ecuadorian and Israeli perceptions of disability at La Joya and Shalva illustrate the shift from medical to social understanding of disability. Through learning about important factors that answer questions of how disability is interpreted and what it means to be disabled, research can pave the way for inclusion and acceptance of disability in our world today and in the future.



REFERENCES

- “2010 Human Rights Report: Ecuador” *United States Department of State*. Bureau of Democracy, Human Rights and Labor. 2011. Web. 20 March 2014.
- Anonymous Participant 1. Interview. Conducted in Jerusalem, Israel. July 2013.
- Anonymous Participant 2. Interview. Conducted in Jerusalem, Israel. July 2013.
- Anonymous Participant 3. Interview. Conducted in Jerusalem, Israel. July 2013.
- Anonymous Participant 4. Interview. Conducted in Jerusalem, Israel. July 2013.
- Anonymous Participant 5. Interview. Conducted in Otavalo, Ecuador. May 2013.
- Baglieri, S., J. Valle, D. Connor, and D. Gallagher. "Disability Studies in Education: The Need for a Plurality of Perspectives on Disability." *Remedial and Special Education* 32.4 (2011): 267-78. Print.
- Bolaños, Melba. Interview. Conducted in Otavalo, Ecuador. May 2013.
- Caicedo, Christian. Interview. Conducted in Otavalo, Ecuador. May 2013.
- Cooley, S. “Bringing the Body to Bear in the Andes: Ethnicity, Gender and Health in Highland Ecuador” *Michigan Discussion in Anthropology* 17.1 (2008): 132-160. Web. 30 March 2014.
- “Disability and Health Fact Sheet.” *World Health Organization*. September 2013. Web. 1 Jan 2014.
- Dorff, E. “Mishaneh Ha-Briyyot: A New Jewish Approach to Disabilities” *The United Synagogue of Conservative Judaism*. n.d. Web. 15 March 2014.
- Drake, R. *Understanding Disability Politics*. London, UK: Macmillan, 1999. Print.
- Elaiv, D. “My story: Serving in the IDF with Cerebral Palsy” *Israeli Defense Forces Blog*. (2012): n. pag. Web. 20 Feb 2014.

- Emanuel, E., Abdoler, E., Stunkel, L. "Research Ethics: How to Treat People Who Participate in Research." *Clinical Center Department of Bioethics, National Institutes of Health* (n.d.): n. pag. Web. 20 March 2014.
- Esparza, Sandra. Interview. Conducted in Otavalo, Ecuador. May 2013.
- Gartner, A. & Lipsky, D. "Disability, Human Rights and Education: The United States" Armstrong, F. & Barton, L. (Eds). *Disability, Human Rights and Education: Cross-Cultural Perspectives*. Buckingham, UK: Open University Press, 1999. 100-119. Print.
- Groce, N. "Immigrants, Disability and Rehabilitation" Stone, J. (Ed.) *Culture and Disability: Providing Culturally Competent Services*. Thousand Oaks, CA: Sage Publications, Inc., 2005. 1-15. Print.
- Gaventa, W. *Jewish Perspectives on Theology and the Human Experience of Disability*. Binghamton, NY: The Haworth Pastoral Press, 2006. Print.
- Hackett, C. & Grim, B. "The Global Religious Landscape" *Pew Research Religion and Public Life Project*. 2012. Web. 20 March 2014.
- Harris, S. "Serving families of children with developmental disabilities: Reaching diverse populations" *Special Services* 12 (1996): 79-86. Print.
- "International Disability Rights Monitor Publications – Compendium – Israel." *IdeaNet*. Center for International Rehabilitation. 2003. Web. 20 January 2014.
- "International Disability Rights Monitor Publications – Ecuador 2004." *IdeaNet*. Center for International Rehabilitation. 2004. Web. 20 January 2014.
- Kress, H. "Explaining the Demographic Transition in Otavalo: A Comparison of Three Models of the Demographic Transition" *Doctoral Dissertations University of Connecticut* (2008): n. pag. Web. 20 March 2014.

- Meaden, H. & Gumbel, T. "Special Education in Israel" *Teaching Exceptional Children* (2002): 16-20. Web. 10 Feb 2014.
- Mont, D. & Loeb, M. "Beyond Disability-Adjusted Life Years (DALYs): Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities" *Social Protection Discussion Papers, The World Bank* (2008): 1-19. Web. 10 Feb 2014.
- Mont, D. "Measuring Disability Prevalence" *Social Protection Discussion Papers, The World Bank* (2007): 1-54. Web. 10 Feb 2014.
- Mont, D. "Measuring Health and Disability" *The Lancet* 369 (2007): 1658-1663. Web. 10 Feb 2014.
- "Overview of International Legal Frameworks for Disability Legislation" *United Nations Enable*. 2007. Web. 20 March 2014.
- Priestley, M. (Ed.). *Disability and the life course: Global perspectives*. Cambridge, UK: Cambridge University Press, 2011. Print.
- "Republic of Ecuador Constitution of 2008" *Political Database of the Americas*. Georgetown University. 2008. Web. 20 March 2014.
- Rimmerman, A. "Israel's Equal Rights for Persons with Disabilities Law: Current Status and Future Directions" *Disability Studies Quarterly Lancet* 25.4 (2005): n. pag. Web. 20 Feb 2014.
- Rogers-Adkinson, D., Ochoa, T. & Delgado, B. "Developing cross-cultural competence: Serving families of children with significant developmental needs." *Focus on Autism and Other Developmental Disabilities* 18.1 (2003): 4-8. Print.

- Schuelka, M. "A Faith in Humanness: Disability, Religion and Development" *Disability and Society* 28.4 (2012): 500-513. Web. 10 Feb 2014.
- Shemesh, Ruth Interview. Conducted in Jerusalem, Israel. July 2013.
- "The Constitution" *The Knesset in the Government System*. The State of Israel. 2005. Web. 20 March 2014.
- "The State of the World's Children 2013: Children With Disabilities" *UNICEF*. 2013. Web. 1 Jan 2014.
- Tobias, M. "Ecuador's Vice President, Lenin Moreno, 2012 Nobel Peace Prize Nominee, Reflects on Human Welfare and the Rights of Nature" *Forbes* (2012): n. pag. Web. 10 Feb 2014.
- "U.N. Salutes Ecuador for Promoting Rights of Disabled People: Ecuador Wins FDR International Disability Award." *IIP Digital*. U.S. Department of State. 2002. Web. 20 March 2014.
- "Visions and Goals" *Shalva: The Association for Mentally and Physically Challenged Children in Israel*. n.d. Web. 20 March 2014.
- Winzer, M. *The History of Special Education*. Washington D.C.: Gallaudet University Press, 1993. Print.
- White, S. & Ingstad, B. "Help for people with disabilities: Do cultural differences matter?" *World Health Forum* 19.1 (1998): 42-46. Print.